

# **NEVADA BIRTH DEFECTS REGISTRY PROVISIONAL REPORT, 2000**

## **Introduction**

This report describes the first year of the Nevada Birth Defects Registry (NVBDR). It is a purely descriptive report of the way that birth defects were distributed by several demographic characteristics of the babies and mothers. As discussed in the Next Steps section, we hope that future reports will include data from other sources (e.g., vital statistics, newborn screening and Medicaid) and provide a more comprehensive analysis of issues related to birth defects. The purpose of this report is to describe the data that was collected during the first year, identify areas of opportunity, and to verify that the surveillance system that was designed and implemented is functioning as it was intended to do so.

## **Background**

Birth defects are one of the leading causes of infant mortality in the United States and in Nevada. As defined by the March of Dimes Birth Defects Foundation, a birth defect is an abnormality of structure, function or metabolism, whether genetically determined or the result of environmental influence during embryonic or fetal life. Besides costing hundreds of millions of dollars in medical and rehabilitation costs each year, birth defects present tremendous emotional and financial stresses for affected families and individuals.

Much remains to be learned about the causes of birth defects. In fact, despite the recent advances in genetics and reproductive biology, nearly two-thirds of birth defects are of unknown causes. Although the cause of most birth defects is unknown, certain factors are known to increase the risk of birth defects. These include nutritional factors, radiation, certain drugs and toxins, alcohol, certain types of infection and other illnesses in the mother, trauma, and hereditary disorders.

One area where substantial progress has been made is in understanding the role that the B vitamin folic acid plays in fetal development. There is now a large body of evidence showing that sufficient consumption of folic acid prior to conception and during the 1<sup>st</sup> trimester of pregnancy can reduce the

incidence of Neural Tube Defects, major anomalies of the central nervous system, by 50-60 percent. Efforts to increase consumption of folic acid by women in their reproductive years, both in food and through vitamin supplements, are underway nationally and in Nevada.

In view of the State of Nevada's history of above and below ground nuclear testing, mining, rapid population growth, 'high risk' behavior lifestyles, and the potential that Nevada will be a nuclear waste dump site, it is vital that baseline data on birth defects be available to the State for public health planning, policy development and research. The development of the NVBDR provides the State with baseline and ongoing data to monitor child health and to design and implement programs to prevent birth defects and improve access for children with birth defects to comprehensive, community-based, family centered care.

### **The Birth Defects Registry**

Based on legislation passed in 1999, the State of Nevada Health Division's Bureau of Family Health Services in collaboration with the Bureau of Health Planning, and the University of Nevada School of Medicine, developed and implemented the NVBDR in January 2000. With the assistance of a CDC grant, the NVBDR was initiated in Clark County (the most populous county) and will soon include the entire state.

The NVBDR includes all infants and children up to age 6 who have been diagnosed with a birth defect (based on the CDC's ICD-9 classification) and are a Nevada resident.

Currently, data is abstracted from hospital records at all hospitals in Clark County and entered into the NVBDR database. Thus, the data in this report is considered provisional because children not hospitalized but being treated through a clinic are not yet included in this report. In addition, since this is the first year of a new surveillance system, over and/or under reporting is likely, but not meaningful.

The following is a descriptive analysis of data from the first year of the NVBDR. As more and more data is collected throughout the state and other vital statistics data is made available for this time frame, other epidemiological analysis can be conducted.

## Data Analysis

During 2000, there were 1,114 Nevada children (0-6 years) who were hospitalized in Clark County and were diagnosed with one or more birth defects. Therefore, there are more birth defects recorded than individual cases. A large proportion of the birth defects involved the heart and circulatory system. Of the 1552 birth defects recorded (see Table 1), 572 (37%) were classified as heart and circulatory defects. Birth defects of the heart (many of which are not severe) may involve abnormal formation of its walls or valves or of the blood vessels that enter or leave it. Many heart defects can be corrected surgically. The timing of the operation depends on the specific defect, its symptoms, and its severity.

Approximately 15% (230) of the defects can be classified as musculoskeletal and limb deformities. These defects include, congenital hip dislocation, clubfeet, and polydactyly (extra fingers or toes). Casting, physical therapy and/or surgery can correct these defects.

Another 11% (166) of the defects involved the genital organs. Thirty percent of these were undescended testis, which is a common abnormality found in male newborns, in particularly in premature births.

Two other major systems that each accounted for over 5% of the defects included the urinary (87) and nervous (79) systems. About 60% of the urinary system defects involved some abnormality of the ureters, usually an obstructive defect.

As for the Nervous system, 14 (18%) of the 79 defects could be classified as Spina Bifida. Spina Bifida is considered a Neural Tube Defect and is strongly linked with a deficiency of folic acid in the diet. Spina Bifida is a condition in which part of one or more vertebrae fails to develop completely, leaving a portion of the spinal chord unprotected. Spina Bifida can often be diagnosed before birth by ultrasound and amniocentesis. A child that is born with severe Spina Bifida usually needs surgery and prolonged, intensive therapy.

Other birth defects of note included cleft palate and cleft lip. These defects accounted for about 4.4% of the birth defects. A cleft lip is an incomplete joining of the upper lip, just below the nose. Cleft palate is an abnormal

passageway through the roof of the mouth into the airway of the nose. Cleft lip and cleft palate can be permanently corrected with surgery.

Finally, a little over 3% of the defects were considered chromosomal anomalies. Down's Syndrome (trisomy 21) accounted for 30% of the chromosomal abnormalities. Down's Syndrome is a disorder that results in physical and mental developmental delays and about 35% of children with Down Syndrome have heart defects.

**Table 1**

<b>Birth Defect</b>	<b>Number</b>	<b>Percent</b>
Heart/Circulatory	572	36.9
Musculoskeletal/Limb	230	14.8
Genital	166	10.7
Urinary	87	5.6
Nervous	79	5.1
Cleft Palate/Lip	68	4.4
Chromosomal	52	3.4
All Other	298	19.2
Total	1552	

### *Infant and Maternal Characteristics*

Of the 1,114 birth defect cases, 661 (59.3%) were males, 443 (39.8%) were females, and 10 (.9%) were unknown (Figure 1). Thus, there was about 1.5 times more males with identified birth defects than females. This observed difference in baby's gender has been found elsewhere<sup>1</sup>.

**Figure 1- Baby's Gender**

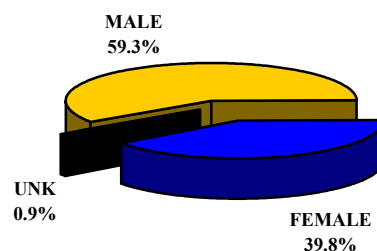
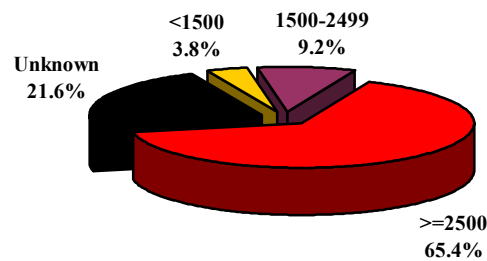


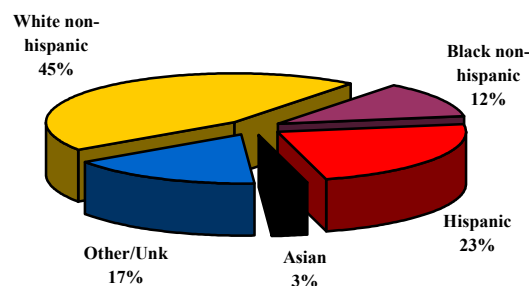
Figure 2 shows the birthweight distribution of the infants identified with a birth defect. A little over 65% of the infants born with a birth defect were normal birthweight (NBW= 2500 grams or more or 5.5 lbs.). About 13% were considered low birthweight (LBW= <2500 grams or <5.5 lbs.) and about 4% were very low birthweight (VLBW= <1500 grams or <3.3 lbs.). About 21% of birthweight was missing for these infants and some of that was due to the fact that when a child is identified as having a birth defect by a post- birth admission, information about the birth was not always available in the hospital chart. Because birth defects occur more frequently in low birthweight infants<sup>2</sup>, it is important that efforts continue to improve data collection and to conduct further analysis.

**Figure 2 - Birthweight Distribution**



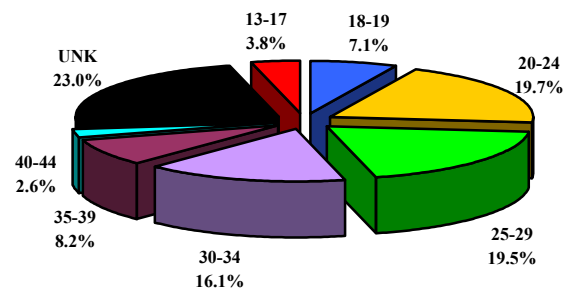
The racial/ethnic distribution of the mothers of the birth defect cases was as follows; 45% were White, 23% were Hispanic, 12% were Black 3% were Asian and 17% were other or unknown. As can be seen, in Figure 3 almost twice as many birth defect cases were born to Caucasian women than to Hispanic women, and there were about twice as many Hispanic births than Black births. National data show that there are certain birth defects that vary by maternal race/ethnicity<sup>3</sup>. Therefore it is again important to improve data collection and to conduct further analysis for this measure.

**Figure 3- Maternal Race/Ethnicity**



The maternal age distribution is shown in Figure 4. As can be seen, young teens (13-17) accounted for about 4% of the births and about 11% were to teens in general (13-19). At the other end of the age spectrum, about 3% of the births were to women between the age of 40-44 and about 11% were over the age of 35. Thus 13% of the mothers who delivered an infant with a birth defect was over 35. This is important because it is well known that certain birth defects, like Downs Syndrome, is more likely to occur to pregnant women over 35<sup>3</sup>. Twenty-three percent of mothers' age was missing in the birth defects database. Again, much of this is because in post-birth hospitalizations there is a lack of information about the mother.

**Figure 4-Maternal Age Distribution**



### Next Steps

The goal of the NVBDR is to create a statewide surveillance system for the early identification of birth defects. In its first year, information on infants and children with identified birth defects was reviewed from all hospitals in Clark County. Expansion into northern Nevada and in rural areas is anticipated for the next year of the program. Another goal of the NVBDR is to analyze the data to facilitate appropriate referrals and to design and implement new preventive programs and coordinate existing services to ensure that children with birth defects have access to the best services available. The NVBDR will continue to furnish reports so that such planning can occur.

Finally, the NVBDR data will be linked with other databases such as vital statistics (this will help capture some of the missing data), newborn screening, Medicaid, other social services data and with other initiatives throughout the state that may be identifying birth defects by other means.

Creating a comprehensive integrated database will furnish important information to public and private health and social service systems and will help in the development of appropriate services, will ensure that all children in need will have access to those services, and will help in the development of preventive programs such as the folic acid campaign.

## **References**

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<sup>2</sup> Birth Defects in Florida, 1996 Data Tables. Florida Birth Defects Registry, Florida Department of Health.

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<sup>3</sup> James L, Erickson J, McClearn B. Prevalence of Birth Defects. CDC Public Health Surveillance for Women, Infants and Children. Division of Birth Defects and Developmental Disabilities, National Center for Environmental Health, CDC, Atlanta, Georgia.

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